# TNSPMP MEETING AGENDA AND NOTES

TNSPMP QUARTERLY TEAM MEETING

TEXAS CHILDREN'S HOSPITAL - CLINICAL CARE CENTER

CONFERENCE ROOM D.0360.40 (3RD FLOOR)

6701 Fannin Street

HOUSTON 77030

THURSDAY – FEBRUARY 19TH, 2009

TNSPMP FACILITATOR: ROBIN SCOTT, OPEN CIRCLE CONSULTING

MEETING NOTES

## **ATTENDEES:**

Sandra Billings	
George R. Buchanan	
Kari Casas	
Donna Claeys	$\sqrt{}$
Robert Crumb	
Margaret Drummond-Borg	$\sqrt{}$
Alice Gong	$\sqrt{}$
Jose L. Gonzalez	
Charleta Guillory	$\sqrt{}$
Cheryl Hermerath	$\sqrt{}$
Scott D. McLean	$\sqrt{}$
Javier Ramirez	$\sqrt{}$
John Saito	$\sqrt{}$
Stuart K. Shapira	$\sqrt{}$
Eileen Sheridan-Shayeb	
Reid Sutton	$\sqrt{}$
Larry Sweetman	$\sqrt{}$
Lois Taylor	V
Brad Therrell	
Surendra Varma	
Sister Mary Nicholas Vincelli	$\sqrt{}$
Morgan Walthall	
Don P. Wilson	√
Jerald L. Zarin	V
Colleen Buechner	V
Becky Roberson	
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Margaret Bruch  Sherry Clay  Mirsa Douglass  Paula Guerin  Eldridge Hutcheson  Daisy Johnson  David R. Martinez  Jann Melton-Kissel  Susan Neill  Sharon Newcomb-Kase  Susan Tanksley  Simran Tiwana  Donna Williams  Susan Snyder  Lisa Kalman  Other Visiting Guests:  Kayan Lewis  Jimi Ripley-Black  Lu-Ann Papile		
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Susan Snyder  Lisa Kalman  Other Visiting Guests:  Kayan Lewis  Jimi Ripley-Black  √	Simran Tiwana	V
Lisa Kalman  Other Visiting Guests:  Kayan Lewis  Jimi Ripley-Black  √	Donna Williams	V
Other Visiting Guests:  Kayan Lewis  √  Jimi Ripley-Black	Susan Snyder	1
Kayan Lewis   √  Jimi Ripley-Black  √	Lisa Kalman	
Jimi Ripley-Black √	Other Visiting Guests:	
	Kayan Lewis	1
Lu-Ann Papile   √	Jimi Ripley-Black	V
	Lu-Ann Papile	1

#### TNSPMP STATUS UPDATE

Mirsa Douglass provided a progress update with an overview of the three phases of the project and year two scope of activities.

## TNSPMP Objectives

- O To identify gaps or deficiencies in pre and post analytical phases of the Texas Newborn Screening System. (Year 1- Completed)
- o To develop and identify evidence-based performance measures and determine their effectiveness. (Year 2)
- o To document specific interventions for which there is a likelihood of improving performance/quality in areas with noted deficiencies. (Year 3)
- TNSPMP Project update since November 2008 meeting
  - O The project scope is limited to reviewing disorders with documented recommendations for timeliness of medical treatment and parameters related to timeliness. Performance measures, having related evidence or literature, have been identified for each of the following disorder and timeliness groups. The list can be found at the end of the meeting notes.
    - Congenital Adrenal Hyperplasia (CAH)
    - ➤ Galactosemia (GALT)
    - ➤ Medium Chain acyl CoA Dehydrogenase (MCAD)
    - Congenital Hypothyroidism (CH)
    - ➤ Maple Syrup Urine Disease (MSUD)
    - Phenylketonuria (PKU)
    - ➤ Sickle Cell Disease (HgSS)
    - Timeliness
- TNSPMP Year Two Activities
  - Complete the identification process of candidate performance measures for disorders of interest and other measures related to timeliness of medical treatment. (Completed)
  - o Select which performance measures will be further developed based on information from feasibility and impact assessments for each candidate performance measure
  - o Implement infrastructure and processes to pilot performance measures in year 3

#### IMPACT ASSESSMENT METHODOLOGY

Mirsa Douglass presented the approach for selecting performance measures to pilot in year 3 with emphasis on the method for impact assessment.

Main presentation points:

- From an approximate pool of 50 candidate measures, TNSPMP system stakeholders will
  recommend measures to be piloted in year three. However, before recommendations
  are made, the existing candidate measures will be prioritized based on two factors.
  Prioritization will be based on results from feasibility ratings (assessed by DSHS staff)
  and impact assessments (assessed by expert TNSPMP system stakeholders).
  - O Degree of impact on clinical outcomes by monitoring performance measure Newborn screening system stakeholders on the TNSPMP who have special expertise with a particular performance area will assign a relative degree of impact of each candidate performance measure using evaluation criterion modified from those suggested by the Agency Healthcare and Research of Quality (AHRQ) National Quality Measures Clearinghouse.
  - o Feasibility of implementing the performance measure As summarized from the November 2008 TNSPMP quarterly meeting, a feasibility rating will be assigned to candidate performance measures. This feasibility score is determined by assessing various aspects of implementation of the measure including data availability, ease of collection, infrastructure and human resource needs, overall cost, and time constraints. Rating will be conducted internally by DSHS newborn screening staff and presented to TNSPMP system stakeholders once ratings have been compiled.
- Figure 1 represents a high-level guideline for how performance measures will be prioritized. As depicted, candidate performance measures assessed as having high impact will be qualified for further consideration to be piloted in year three, while the performance measures having little to no impact will be eliminated from consideration.

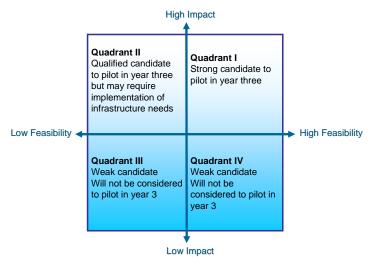


Figure 1: Performance Measure Prioritization Methodology

• Degree of Impact on Clinical Outcome by Monitoring the Performance Measure

- o Many of the elements for measuring impact suggested by system stakeholders from the TNSPMP quarterly meeting in November 2008 parallel with the conceptual framework provided by the AHRQ National Quality Measures Clearinghouse for evaluating standard health-related performance/quality measures.
- o TNSPMP system stakeholders will be asked to appraise each candidate measure against a modified version of evaluation criteria suggested by AHRQ (http://www.qualitymeasures.ahrq.gov/resources/measure\_use.aspx#attributes).
- o Evaluation criterion will include various topic areas:
  - Relevance to stakeholders
  - > Health importance
  - Applicable to measuring the equitable distribution of health care
  - > Potential for improvement
  - Susceptibility to being influenced by the health care system
  - Explicitness of evidence supporting the performance measure
  - > Strength of evidence supporting the performance measure
- Impact Assessment Groups TNSPMP system stakeholders, based on their area of expertise, will be grouped into one or more of the following impact assessment groups. Stakeholders will be asked to assess the impact for each of the performance measures associated with their assigned group. Stakeholders will have the opportunity to determine if they have been assigned to the appropriate group(s).
  - o CAH Performance Measure (PM) Assessment Group
  - o Galactosemia PM Assessment Group
  - o CH PM Assessment Group
  - o PKU PM Assessment Group

- o Sickle Cell PM Assessment Group
- o MCAD PM Assessment Group
- o MSUD PM Assessment Group
- Timeliness PM Assessment Group
- TNSPMP system stakeholders will assess impact based on the evaluation criterion for each candidate performance measure in their assessment group.
- Results from each of the expert stakeholders will be processed systematically and results
  will be presented in aggregate once results have been compiled. In reviewing results,
  DSHS will note assessment responses having a lack of consensus.

## SICKLE CELL PRESENTATION

Simran Tiwana presented evidence-based performance measures for Sickle Cell.

#### **DEVELOPMENTAL FOLLOW-UP**

Dr. Lu-Ann Papile, professor of pediatrics at Baylor College of Medicine, gave a presentation on neonatal developmental follow-up.

## NEWBORN SCREENING STATE REPORT CARDS

Mirsa Douglass provided survey results found from state "report cards" or performance feedback mechanisms used by other states. Presentation highlights:

- Forty three states responded as either utilizing a "report card" for quality assurance purposes or indicated that a "report card" was not used by the state program.
  - o 30 of the respondents provide "report cards" for the purpose of quality assurance and the remaining 13 respondents do not provide report cards to their newborn screening submitters

The presentation provided insight on how measures were reported for feedback areas including specimen quality, timing of specimen collection, specimen transit, specimen demographic information, and other miscellaneous information.

# TNSPMP PROJECT FEEDBACK

Robin Scott requested feedback from stakeholders on the success of the project.